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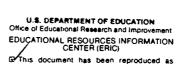
This report attempts to define the telecommunications requirements and support services needed by mentally retarded users in Sweden. It focuses on population, definitions, and classifications of mental retardation, and implications of mental retardation in daily living. Support services including medical care, habilitation, and education for people with mental retardation are also discussed. The importance of communication for people with mental retardation is emphasized and a plan to pilot the use of videotelephones for this population is presented. For this effort, client characteristics, benefits, equipment and network requirements, service classification, and service procedures and staffing are considered. (Contains 20 references.) (DB)

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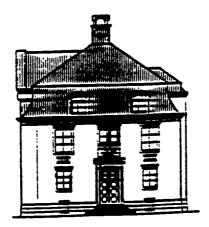
TELECOMMUNICATION FOR PEOPLE WITH MENTAL RETARDATION

Requirements and Services

Jane Brodin

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TELECOMMUNICATION FOR PEOPLE WITH MENTAL RETARDATION

Requirements and Services

Jane Brodin

This report is written in the start-up process of the European RACE 2033 project (Research in Advanced Communications Technologies in Europe), TeleCommunity, which is financed by the Swedish Telecom and the Swedish National Board for Industrial and Technical Development (NUTEK).

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Abstract

Brodin, Jane (1992) Telecommunication for People with Mental Retardation. Requirements and Services. Report No 3 in the series Technology, Communication and Disability, Department of Education, Stockholm University, Sweden.

The objective of this report is to define the requirements and support services for mentally retarded users within the telecommunication area. The report focusses on population, definitions and classifications of mental retardation, as well as implications of mental retardatior in daily living. Support services as medical care, habilitation and eduation for people with mental retardation are also discussed in the report.

The importance of communication for people with mental retardation is emphasized.

In the report a plan to pilot the use of videotelephones for this population is presented.

Keywords: User requirements, support services, telecommunication, videotelephony, mental retardation, argmentative and alternative communication (AAC)



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1. INTRODUCTION

1.1 Background

People with mental retardation are people in need of special support for their daily living. In order to have access to services in the community and to be able to participate in social activities at 'normal' living conditions people with mental retardation sometimes require more support than other groups of disabled people due to intellectual, cognitive, motor and social factors as well as the comprehension of additional handicaps. About 50% of this population also have multiple handicaps in addition to the mental retardation. The term multiple handicap means severe disabilities while the term additional handicap means milder disabilities. If also people with smaller additional disfunctions are included the percentage will increase to about 67%. This figure increases the more severe the mental retardation is, which means that about 95-100% of all persons with profound mental retardation have also several additional handicaps (Brodin, 1991).

Today people in Sweden with mental retardation are not registered and this makes it difficult to rely on statistics of the number of people with mental retardation living in the country. This is due to the fact that people with mental retardation have to ask for special support according to the Act on Special Services for Intellectually Handicapped Persons. Only those who demand special services are registered by the authorities.

In 1985 17.800 children with mental retardation (between 0 and 19 years) were registered. After revision of the law in 1986 the rules were changed and this figure has decreased. In 1991 8.335 children with mental retardation were registered. This does not mean that the number of children with mental retardation has diminished. The real reason for this decrease is as a matter of fact that these children and their families receive support from other sources in community e.g. municipality, preschool, school and habilitation in the framework of all citizens' rights. However, the most common additional handicaps for all categories of people with mental retardation are motor disability, language or communication disorders, visual impairment and epilepsy. This shows that the situation is extremely complex.

1.2 Domain and population

In Sweden about 0.45% of the total population is classified as mentally retarded. This means that there are about 38.000 persons (about 17.000 children, 0-19 years) in Sweden belonging to this group. In the USA the percentage is twice or in some states six times as high, i.e. 2-3% of the



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total population (Bakk & Grunewald, 1986). In general, however, a reasonable estimation is 1% of the total population in the western world. This means that there would be about 5 million persons with mental retardation in the whole of Europe, where 500 million people live, according to information from the Swedish Institute of Foreign Affairs. If the higher percentage, i.e. 3% is used, the figure will be 1.500 million persons with mental retardation in Europe. The lower figure for Sweden (0.45%) depends on the fact that many steps have been taken by the social and legal authorities in order to compensate for the disability in the community. The concept of handicap is thus a relative concept.

Most people consider it as a matter of course to be able to participate in activities in society and to use facilities offered. To have access to TV and to be able to use telecommunications seem to be basic needs today. Most people even regard it as impossible to live without a telephone. For people with mental retardation speech and communication is often difficult and complicated. Previous activities within the telecommunication area have primarily focussed on individuals with visual impairment, hearing impairment, motor disability as well as elderly people in general. Few activities have been conducted in the area of mental retardation which depends on the fact that there has been a lack of knowledge of mental retardation as well as telecommunication per se. The possibilites to get access to services in society has been emphasized during the last decades for this population (Brodin & Magnusson, 1992).

An evaluation of still picture telephony for children and adults with moderate mental retardation has shown that if the equipment and the environment are adapted to respond to the user's requirements, the possibilities to use telecommunication facilities will increase also for this population (Brodin & Björck-Åkesson, 1991). The experiences of still picture telephony for people with profound mental retardation point to the same direction, but the use seems to be more important for social and emotional reasons (Brodin & Björck-Åkesson, 1992).

1.3 Objective of this report

The overall objective of this report is to define the requirements of mentally retarded users within the telecommunication area and to define the framework of services. Definitions and classifications of mental retardation as well as implications of the disability in daily living are discussed. Requirements of support and services available in Sweden as medical care, habilitation and education are illuminated.

One objective is also to introduce a project plan to pilot the use of videotelephony for communication and support services for people with mental retardation. This report can be regarded as the starting point. The



project consists of two parts, a mini-trial and a main study. A plan for carrying through the mini-trial is presented in this report as well as client characteristics, benefits, equipment, service classification, procedures, staffing and service loading for the project as a whole are in focus. The main study covering six day care centers is briefly presented.

The report is based on litterature studies and draw forth primarily a theoretical discussion about the difficulties and possibilities of giving support to people with mental retardation in order to facilitate communication and support services from society, especially with regard to telecommunication.

2. MENTAL RETARDATION

2.1 Definitions and classifications

The view on people with mental retardation has varied during different periods, and so has the term used to describe the disability. Many different terms are today used to describe mental retardation, e.g. mental/intellectual handicap, mental/intellectual impairment, developmental disability/disturbance and mental/intellectual delay. Sometimes the term slow learners or people with difficulties in reading and writing are categorized as intellectually handicapped and included in this population. Different terms are used in different parts of the world and by different categories of professionals.

In many countries the terminology has been changed and substituted by new expressions. One reason for changing terminology seems to be a need to change words, which are negatively loaded in order to influence the attitudes. However, this change is sometimes a problem as you can never be sure that you talk about the same population when you exchange information with researchers and professionals from other countries. Definitions are intended to be tools to facilitate understanding between human beings in order to avoid complications due to language differencies. In general, I have chosen to use the term mental retardation in this text, but also other terms occur. The greater part of the national handicap organizations and associations all over the world still use the term mental retardation, but a change seems to be on it's way. Changing terminology will not change the attitudes, but can probably mix things up and diminish the possiblities to be sure that we talk about the same population. In scientific journals and newsletters this term is mostly used. However, the above terms are often used synonymously. It is important to stress that mental retardation/impairment has no connection with mental illness.



One reason for defining mental retardation is to be able to work out models to classify, assess and to take measures to facilitate and compensate for the impairment. World Health Organization (WHO, 1980) classifies mental retardation in four degrees: deep, severe, moderate and mild and relates these to Intelligence Quotient (IQ).

Table. 1 WHO's definition of mental retardation in relation to IQ

Degree of mental retardation	Deep	Severe	Moderate	Mild
ĪQ	< 20	20-35	35-50	50-70

The distinctions between the different levels are arbitrary and are based on statistical lines. These principles for categorization can be used for adults with mental retardation, but it is not applicable to use IQ as a base for categorization of children. The reason is, that there are great difficulties to measure IQ in children and sometimes also in adults with mental retardation as they can or will not contribute to tests. Another reason might be that they do not understand how to perform the tests. WHO's classification system is used in many countries, others classify mental retardation into mild, moderate and severe (or profound) retardation.

In Scandinavia the latter terms are used. The Swedish researcher Gunnar Kylén (1981) has developed a theory describing intellectual development in relation to mental retardation. Table 2 displays the principles for categorization.

Table. 2 Kyléns classification in relation to WHO's definition of mental retardation and IQ (based on Kylén 1981)

Degree of mental retardation		Deep	Severe	Moderate	Mild
ĪQ		< 20	20-35	35-50	50-70
A-B-C level Kylén	A <10	,	В		С

Kyléns theory is mainly based on Piaget (1962) and is founded on levels in child development. This means that the A-level corresponds to an age below 18 months, the B-level from 18 months to seven years and the C-level from seven to twelve years of age. An adult can thus have a biological age of 25 years, but a developmental age of twelve years.



However, the life experience and functional ability must be taken into account when one assesses the level of development.

Furthermore the American Association on Mental Deficiency uses another scale for classification. According to their schemes mild mental retardation corresponds to an IQ of 55-70, moderate from 40-55, severe from 25-40 and profound below 25 (cf Kylén. 1981). If this scale is related to the above the result would be:

Table.3 Kyléns classification in relation to WHO's definition of mental retardation, IQ and AAMD (based on Kylén 1981)

Degree of mental retardation		Deep	Severe	Moderate	Mild
ĪQ		< 20	20-35	35-50	50-70
A-B-C level Kylén	A <10		В		С
AAMD		<25	25-40	40-55	55-70

From the above table it is evident that different scales are used by different organizations. There are similarities but there are also differencies.

Mental retardation can also be classified according to other rules. A person whose intellectual capacity deviates downwards from 'normality' can be described as mentally retarded. The concept normality shall be understood in relation to the average, the normal curve, of the population. However, the concept normality is not uncomplicated at all. What is regarded as normal can vary in different societies and cultures, but also in different social groups. Another factor is that the rules for normality is set out by people who regard themselves as normal. For example, it is of course quite normal for a person with disability to be disabled. I will not discuss this issue any further but think it is important to regard it as a factor when discussing the concept normality. The normalization principle originates from the fifties (Nirje, 1969) and is based on democracy, solidarity, equality and participation for all citizens in community.

The ability to understand what one sees, hears and experiences and to think in abstract terms is impaired or retarded in people with mental retardation. The ability to perceive, process and to store information is reduced. This is a psychological definition of mental retardation. The social definition includes that an individual who cannot meet the requirements in community, can be described as mentally retarded from a social point of view. The level of the requirements of support and the



adaption of the environment where the person lives is crucial for classifying people as mentally retarded or not. If the environment is adapted to the person with an impairment, he or she is not necessarily handicapped. Handicap originates when a person with disability is confrontated with the environment (WHO, 1980).

The psychological and social definitions and effects of mental retardation are closely related to each other and cannot be separated. That's the main reason why persons with mental retardation need a comprehensive support from the community.

Today also other methods are used to define and assess mental retardation. The most important way is to make assessments of the functional level of the individual (Seibert & Hogan, 1982; Uzgeris & Hunt, 1975). They have developed qualitative scales for assessment of social communicative skills and child development. These scales seem to be very useful for people with mental retardation and multiple disabilities. Nielsen and Petersen (1984) have developed a scheme to assess the functional level and learning abilities primarily in children. The conclusions of these scales are that the most important thing is to find out what the child or adult can do today e.g. the actual ability, how to give the best support in order to compensate for the disability and to support the development of the child.

In Sweden a person is classified as mentally retarded if he or she before the age of 16 incurs a deficiency or injury impairing his mental ability to such an extent that he requires special daily support and assistance in order to participate in social activities in the community. Psychological, social, educational and motorical factors all have to be included in the assessment of the ability. This definition follows the recommendations by the WHO.

2.2 Implications of mental retardation in daily living.

In order to define intellectual capacity it is necessary to understand the implications of mental retardation. Intellectual capacity encompasses a concept of reality that is built up by processing sensorial experiences and it is organized by the thought process. Symbols (pictures and language) are used to assist the thought process, but they are also important for communicative interaction with the environment.

The first function of the intellect is to structure the impressions. Sensory impressions are organized into five categories: the concept of space, the concept of time, the concept of quality, the concept of quantity and the concept of cause (Kylén, 1981). By structuring the sensory impressions the above concepts can be organized. The second function is to make concrete and abstract thought operations and the third is to symbolize objects and events. Structuring, operating and symbolizing can be



performed at different abstraction levels. These levels increase during the intellectual development (A, B, C levels), but will not reach the level of normal development. People with mental retardation have the same feelings and needs as non-disabled people, but their self-esteem and self-confidence are influenced by the attitudes and treatment they receive from people in the environment.

To conclude:

A person with mental retardation has a lower capacity of the short time memory than a normal person. This deteriorates the learning ability. He/she has difficulties in perceiving, processing and storing information.

The abstraction level is lower than normal. This means that he/she needs concrete operations and a concrete environment. He/she cannot make plans for the future and the concept of reality is simple (Kylén, 1981).

Speech, language and/or communication disorders are common. About 70% (Luftig, 1982) of all persons with mental retardation and about 95% of persons with profound mental retardation have communication disorders (Brodin, 1991; Brodin & Lindberg, 1990).

The ability of perception is often disturbed and he/she has difficulties to discriminate and perceive sensory impressions.

A person with mental retardation needs more time to learn to understand pictures and symbols and he/sh needs more training to do so.

For children with mental retardation it is obvious that they are slow learners and that they have a slower development than other children. Many researchers today discuss if the development of children with mental retardation follows the same steps as those of children with normal development or if the development is 'disability specific'.

Mental retardation cannot be cured, but to some extent compensated. The keywords for compensating mental retardation is training, repetition, structure, concreteness, continuity as well as social, educational and technical support. If a person with mental retardation get support, he/she has great possibilities to develop and live a good life.



3. COMMUNICATION, TELEPHONING AND MENTAL RETARDATION

As mentioned above a mentally disabled person has a simpler and more concrete concept of reality than a person with normal intellectual ability. The difficulties are related to perception, guiding/operating, symbolizing and to memory functions. Many people have communication disturbances and disorders. In spite of the fact that great efforts have been made during the last few years, mentally retarded people are a neglected group with regard to communication aids and support. This is true especially of adults who have not had access to any alternative ways of communication in their lives.

Today most adults with mental retardation live in group homes as the big institutions in Sweden have closed or are closing down. This is due to legal issues but also to ideological reasons. About 6.000 adults and about 140 children below the age of 20 years are still living at institutions in Sweden. There is a goal in the handicap policy to abolish all institutions and this work is going on continously. The problem is to find suitable homes for the adults and to offer meaningful daily activities e.g. day care centers or work in sheltered workshops. The situation today is that there is a lack of working possibilites for adult people with mental retardation.

About 20 children below the age of seven are still living at institutions (Grunewald, 1986). These children need qualified medical care and support and their families do not feel capable to take care of them. The goal is to find suitable family homes (earlier called foster homes) for these children. The prinicples of normalization and integration are leading in Sweden.

However, it has turned out that consistent and well adapted communication training together with suitable communication aids can enable many mentally retarded persons who cannot use speech today, to communicate (Brodin & Björck-Åkesson, 1991; Granlund & Olsson, 1987; Johansson, 1988; Kraat, 1985). Even if the communication is limited, it can contribute to the person's capability to exert influence on the environment and make his own choices, which is important for personal development, independence, self-esteem, participation in social life and will improve the quality of life.

Telephoning is a way to communicate even if it can be difficult and complex for many people with a mental disability. The communicative competence depends on the individual's status (physical and psychological), on the environment's requirements and status (physical and social), and on the access to AAC (Augmentative and Alternative Communication). Alternative means a substitute for (or alternative to) natural speech and/or writing. Augmentative means an approach which is



an addition to natural speech and/or writing. "It should not be used if there is no natural speech and/or writing involved" (Lloyd & Kangas, 1990). Among other things, the person must be motivated and willing to communicate, and in possession of sufficient perceptual functions and motor ability. Light (1989) has described a model of communicative competence in terms of functional aspects, sufficiency and individual skills. Skills are subdivided into operational capacity, linguistic capacity, social capacity and strategic capacity. When it comes to using videotelephony all these aspects are relevant and important to consider (Brodin & Björck-Åkesson, 1991, 1992; Brodin & Magnusson, 1992).

The communication process is dynamic, and the various steps interact continuously. The will to communicate depends on motivation, implying that you have to know what you want, how to attain the objective and what you get from reaching the goal. A mentally retarded person has a limited short time memory, and in many cases a limited motor ability. The short term memory can be compensated by repetition, reorganization of information, integration into bigger, more meaningful units and automatism. Recognizing is for instance easier than remembering and it is easier to dial a telephone number which is well-known than to learn a new one. Even if he/she gets help to dial, he/she may have no message to bring across or may not understand that the voice does not originate from the telephone receiver but from a person sitting somewhere else, perhaps at a long distance (Göransson, 1984).

A previous study on still picture telephony for moderately mentally retarded children and adults has shown that the combination of voice telephony and still picture transmission facilitates communication and increases the possibilities for establishing social contacts, which in reality means increasing the quality of life for these persons (Brodin & Björck-Åkesson, 1991).

4. REQUIREMENTS FOR PEOPLE WITH MENTAL RETARDATION

4.1 General requirements

Telephoning imposes requirements both on the individual and on the environment. A basic requirement for the individual is to become motivated to use the telephone and be interested in using the telephone for ordinary communication. Another requirement is to have access to appropriate social support from persons in the environment when needed. The attitudes of the people around are thus of great importance. If the support is good and positive the mentally retarded person will be encouraged and stimulated to communicate and to use the telephone.



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Light's (1989) model of communicative competence in terms of functional aspects, sufficiency and skills, has shown that especially operational and sociorelational abilities are necessary for telephoning. In other words, the telephone equipment must be adapted to suit the person who is going to use it.

There are, as mentioned above, about 5 million individuals with mental retardation in Europe and about 60% of these persons are mildly or moderately retarded. It is reasonable to believe that persons with mild and moderate mental retardation could make good use of videotelephones. Most of these people have difficulties to communicate and often use picture or 'sign communication' as a complement to a poorly developed speech. Sign communication is a simplification of deaf people's sign language and the users are people with mental retardation. They do not use telephones for communication today, but if they had social support from educated staff they would probably be able to use videotelephones. Using two channels for information (visual and auditive) at the same time increases the possibilities to understand.

The staff involved in communication activities are often occupational therapists, speech therapists and special teachers working at day care centers, special schools or local habilitation centers. Family members are also often working with communication training. Videotelephones can be used at day care centers, group homes, family homes, sheltered workshops, special schools, habilitation centers etc. However, it is necessary to point out that the communication partner, in this case the receiver of the telephone call, must also have a videotelephone. In other words; the videophones can be used everywhere where a telephone is used in order to facilitate communication and make it possible for people with mental retardation to participate at the same conditions as other citizens in community.

4.2 Main objectives of using videotelephones

Still picture telephony has shown that visual and auditory information facilitates for a person with moderate or profound mental retardation to understand a message and stimulates communication. For people with moderate mental retardation, who use sign communication as support to the spoken language, a videotelephony would probably be a good solution.

The objectives of using a videotelephony could be:

- to facilitate, support and improve communication
- to support and establish social relations
- to stimulate and encourage people who do not communicate
- to have access to the telecommunication net in an ordinary way



- to support independent living
- to be a cognitive tool to structure the daily living

The vidoetelephones could also be used as support in educational situations at schools and at habilitation centers. The use of videotelephones requires support from engaged staff, and of course someone to communicate with.

4.3. Equipment

The equipment must be adapted to suit the requirements and the cognitive level of the mentally retarded person as well as the environment. One condition is that the videotelephone should be easy to use. It is important to make sure that no difficult operations are involved when using the telephone. It is an advantage for people at low developmental levels if as few moments as possible are involved when operating the telephone. A loudspeaking telephone for instance makes it possible to use both hands when operating the telephone. To mark the buttons on the telephone for "sending and freezing snaphots" facilitates the operation.

Motor disability can cause difficulties in telephoning and an automatic dialler may be suitable. The dialler with programmed telephone numbers can be marked with photos or pictures in order to make it easier to make a call. Another adaptation can be to connect a loudspeaking telephone, to use touch contacts to activate the telephones etc.

The possible technical solutions are numerous and technicians at technical aids centers should help adapting auxiliar communication equipment.

4.4 Summary - General aspects

The main objective of the Swedish pilot project is to offer people with mental retardation possibilites to get access to the same services offered to other people in community, but with necessary adaptations corresponding to their level of development. The aim is to offer all citizens full participation in community, independent of their disabilities.

People with mental retardation are not a homogeneous group. There are differences between individuals, but there are also differences between different functions in the same individual, i.e. a person can be very good at perceiving sensory impressions, but not be able to organize and interpret the impressions. Sometimes the additional impairments influence very negatively on the mental retardation per se and this means that the difficulties must not only be added but multiplied.



Most persons with mental retardation have no, or poorly developed, spoken language and therefore need alternative ways to communicate. One way to promote and encourage communication is to use picture telephones to support the communication ability and to improve the quality of life.

5. SERVICE FOR PEOPLE WITH MENTAL RETARDATION

People with mental retardation have the same rights as other citizens to lead a good life. The keywords are equality, democracy, solidarity and participation in various activities in community. In order to fulfil these goals people with mental retardation need special support and require more assistance than others.

What the mental retardation means and what the implications are in daily life have been described above. The service situation differs between countries. The existing services provided in Sweden are described below.

5.1 Services available in Sweden

Service for people with mental retardation is provided by the government, county councils and municipality. These authorities are responsible for almost all public services within important sectors such as the employment services, education, medical care and social welfare. Sweden has also a strong and powerful handicap movement and they influence decisions in the Parliament with regard to the handicap policy. This movement consists of people of and not for people with disabilities and about 35 associations represent different groups of disabled people. Services for people with disabilities are not provided on a volontary basis.

The goal of Swedish handicap policy is to avoid special solutions for people with disabilities as far as possible and instead make the society as a whole accessible to all citizens. In contrast to some other countries Sweden has no general law aimed to secure the rights of people with disabilties, but has special paragraphs integrated into certain laws e.g. the Building Act, the Social Service Act. One exception from this rule is the Act on Special Services for Intellectually Handicapped Persons (revised in 1986). This law applies to special services and is a complement to other laws. The support one can require from this law is:

- consultation, individual support from a contact person or specialist
- daily activities in day care centres or other activities for those who have left school and are not in education



- short stays at short time homes in order to give parents, siblings and other relatives some spare time and opportunities to rest
- residence in foster homes, boarding homes or group homes for children and young people who cannot live with their parents
- group homes for adults who are unable to live by themselves

People who require help according to this Act have to apply for support. This means that they do not get any help automatically, but must apply for special support.

In addition to this, people with disabilities can get home help service and transport service. In recent years there has been a trend towards transferring people from institutions to various forms of independent, integrated housing. This trend is specially noticeable for people with mental retardation. In the group homes, four or five people live together in a flat or a house. Each person has his/her own room but they often share kitchen and living room. They have staff to attend and help them.

5.2 Medical care and habilitation

The ordinary medical service is intended for mentally retarded people as well. The county councils are responsible for the habilitation and rehabilitation.

There are special centers for people with visual and hearing impairments and there are also special consultants for these people. The habilitation for people with mental retardation includes medical, psychological, social and pedagogical support. The medical support is attended to by doctors, occupational therapists, speech therapists and physio therapists. The pedagogical support for children with mental retardation is given by special teachers e.g. toy librarians or special educators. The different categories of service suppliers are working in teams in order to give the child/adult and the family a total support.

In the habilitation area it is important to mention technical aids. All people with disabilities can obtain technical devices free of charge, i.e. as a principle. Due to economical and other limitations it is, however, not always possible for an individual to get what he or she really wants. The technical aids centers test, prescribe, adjust and give information about technical devices. They are also responsible for the adaptation and training which are important parts in the habilitation process of people with mental retardation.



5.3 Education

The main principle with regard to education is that people with mental retardation have the same right to education as other people. There are special schools for people with mental retardation. These include special comprehensive schools, training schools and special vocational schools. The special schools are usually located in the same buildings as the ordinary schools.

Today almost all children with mental retardation attend the local ordinary preschool. The municipality has the responsibility to offer a place for all children, but children with disabilities have priority. The physical integration is thus a fact. However, integration should also include a social and functional aspect in order to fulfil the demands of beeing considered integration.

With regard to compulsory school about 900 pupils with mental retardation (1991) are individually integrated into ordinary classes. There is a tendency that parents to a higher extent than earlier require a place in ordinary schools for their children. At present there is a discussion about integration and if it is positive or not to integrate children with mental retardation in ordinary schools. The definite decision should be taken by the parents and the school authorities have to accept their decision.

Many adults with mental retardation have not had an opportunity to go to school when they grew up. The law of 1967 made it possible also for people with profound mental retardation to go to school and today many adults get or have got special educational training.

6. PILOTS

6.1 Videotelephony - Client Characteristics

The videotelephony service is designed for adult people with moderate mental retardation. Additional disabilities are no obstacles, but the primary disability should be the mental retardation. The intention is to promote and encourage people to communicate and to use videotelephones in the same way as other citizens in community use telephones to communicate. The people participating in this pilot project live in group homes or in family homes with their parents and they work at day care centers at day time. They are adults between 22-50 years of age with a moderate mental retardation.

The mini-trial will be set up in two different rooms at one day care center. This day care center has been defined and is in fact a day care



center where the main tasks are to work with communication. For the main study the equipment will be installed at six different day care centers and the intention is to have four or five individuals with mental retardation using the videotelephones at each day care center. The intention is to extend the social network of the participants in order to support communication between the individuals from the six day care centers involved.

6.2 Client benefits

The use of videotelephones will encourage communication and increase the possibilites for people with mental retardation to participate in social life. It also seems to be important to increase the level of independence and integration and to improve the communication ability. The benefits will also be that the participants in the project will be able to keep in touch with friends and to be able to develop and establish their social networks. The overall aim is to improve the quality of life.

6.3 Equipment and network overview

The system planned to be used is six "64 kbps" videotelephones (probably according to the 2 x 64 kbps ISDN standard). Special adaptations with regard to the equipment must be made to suit the developmental level of the participating persons. The pilot project will be carried through in an area of about 200 km round Stockholm in order to keep costs down but also in order to provide swift assistance to the staff at the day care centers. There are good reasons for believing that the system will cover the whole nation in the future.

During the mini-trial the equipment will be tested, that is size of screen, speed of transmission of the picture and position of the camera. Another thing that seems to be important is to chose a good location for the equipment. Will it be possible to have the videotelephones in the same room as other activitites are going on or is it necessary to have a separate room for the equipment?

6.4 Service classification

The service is provided on terms of elementary communication, but also as support for social integration and to establish social relations. This means that the service is part of the ordinary telecommunication service and that the communication is based on man-to-man communication but the connection will be from unit to unit and communication from group to



group is also possible. The service can however be regarded primarily as a dialogue service. The day care centers are responsible for the ADL-training (adaption to daily living) and communication is regarded as part of this training.

6.5 Service Procedures and Staffing

The procedures to use the videotelephones require staff from the day care centers to be present. At the beginning the staff will have to take initiatives to make telephone calls but one goal is to increase the motivation and will of the mentally retarded persons so that their interests to use the videotelephones increase. This is especially important with regard to independence. There is also a possibility that the whole group (four or five people) at one day care center communicate with a group at another day care center at the same time. This will be a conference meeting.

The videophones allow the people with mental retardation to use the telephones when they can manage. Everything depends on the participating persons and their abilities. Each day care center can call five other day care centers. At each day care center there are four or five participants. There are discussions going on between researchers concerning the requirements of the picture for transmission and many seem to believe that the quality of the picture must not be very high when you are going to use it as a complement to the speech (Brodin & Magnusson, 1992). However, it seems to be important that sound and picture are transmitted synchronized as it otherwise will be confusing for people with mental retardation. The size of the screen must probably be bigger than was the case with the Panasonic still picture telephones as the participants this time will use sign communication and pictures.

The staff involved is the ordinary staff from the day care centers. Most of the staff involved are occupational therapists, speech therapists or care nursers. The staff (one main responsible and at least two or three persons as co-trainers) have to

- be interested in learning how the equipment works
- be motivated and positive to teach and train the test person to telephone
- be willing and able to spend time on training
- be willing to document the work in writing
- produce diary notes according to a special scedule

The requirements on the staff are fairly high but earlier project experiences have shown that it is important to inform the staff from the start that the trials will consume much time. If they know from the start that it will not be possible to obtain this time for training it is better not to



attend to the project. It also seems advantageous to inform the head of the social services in the county councils what's going on in order to support the staff.

The specific task the staff have to carry out is to be the "helping hand" for the participant with mental retardation. In this telecommunication project relatives are not going to assist. The staff will work with telecommunication within their ordinary working time.

The videotelephoning will need time but for staff at day care centers this may be a positive activity to train ADL (adaption to daily living). The time for each individual shall not be restricted but one telephone call a day seems reasonable to ask for. This must be decided later on when the project has started and the first evaluation with the staff has taken place.

7. CONCLUSIONS

The requirements of people with mental retardation to use videotelephones and the services provided in the society are discussed in this report. The main study on a comprehensive social evaluation will start in 1993. The project will be carried through at the Department of Education, Stockholm University, by Jane Brodin and Magnus Magnusson. The technical evaluation will be effected as soon as the mini-trial has been finished. Responsible for the technical equipment is Sven-Håkan Nilsson, Daltek Inc. and coordinator for all telecommunication activites in Sweden is Jan-Ingvar Lindström, Swedish Telecom.

The mini-trial will start in September and go on for 6-8 weeks. During this time the ideas to adapt the equipment will be tested. There are many questions to be raised at the start position and there are many challanges to meet. It is therefore important to build a system with flexibility and not a system which will not be able to develop and expand afterwards. The project is financed by the Swedish Telecom.

The results of the study will to a high extent depend on the participants and their abilities and disabilities. If the results of the videotelephony turn out to be positive, the service will be part of the ordinary telecommunication service in the future.



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